DOCUMENT RESUME

ED 331 211 EC 300 192

AUTHOR	Horne, Richard, Ed.
TITLE	Having a Daughter with a Disability: Is It Different for Girls?
INSTITUTION	Interstate Research Associates, Inc., Washington, D.C.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	Oct 90
CONTRACT	G0087C3051
NOTE	17p.
AVAILABLE FROM	Interstate Research Associates, NICHCY, P.O. Box 1492, Washington, DC (individual subscriptions free).
PUB TYPE	Guides - Non-Classroom Use (055) -- Reference Materials - Bibliographies (131) -- Collected Works - Serials (022)
JOURNAL CIT	NICHCY News Digest; n14 Oct 1990
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Child Rearing; *Disabilities; Elementary Secondary Education; Employment; *Females; *Independent Living; Personal Autonomy; *Self Determination; Sex Differences; Social Life

ABSTRACT

This guide focuses on some of the realities parents must face in helping their daughters with disabilities to become more self-reliant and, ultimately, independent. The degree to which daughters with a disability are encouraged to strive for an independent life may be critically less than for sons. These differences have far-reaching implications for how males and females view themselves and what they achieve. The guide gives a general overview of gender issues and some suggestions for promoting self-sufficiency and independence. Steps towards independence include starting early, recognizing the influence of the family's behavior, and assessing parental expectations and level of assistance and the disabled girl's motivation. The guide also discusses the importance of developing a social world, confronting the world of school and work, and having role models. A list of 37 books, educational materials, films, videotapes, and organizations is included. (28 references) (JDD)

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ED 330211

N.I.C.H.C.Y.
News Digest

National Information Center for Children
and Youth with Handicaps
Washington, DC

Having a Daughter With a Disability: Is It Different For Girls?

Number 14
October, 1990

This issue of NEWS DIGEST focuses on some of the realities parents must face in helping their daughters with disabilities to become more self-reliant and, ultimately, independent. You may ask, "Why a special issue on gender? Are the issues really that different for boys and girls?" The answer is: Yes. While the issues of independence and self-determination obviously apply to sons with disabilities as well as to daughters, the degree to which daughters with a disability are encouraged to strive for an independent life may be critically less. The psychological and feminist literature inform us that these are issues of society in general, with important differences existing in how males and females are socialized, counseled, and educated. These differences have far-reaching implications for how males and females view themselves and what they achieve.

Statistics tell us that females with disabilities are achieving less in terms of employment and socialization into the mainstream of life than men with disabilities, with the vast majority of women living in dependent and comparatively impoverished circumstances. Yet, there are many girls and women with disabilities who flourish and succeed. What are the reasons for their success, when others do not succeed? How can parents and professionals foster self-confidence and aspirations to employment and independence in young women with disabilities?

*Within this **NEWS DIGEST** you are given a general overview of gender issues and some suggestions for promoting self-sufficiency and independence. But most of all, this **NEWS DIGEST** is intended to increase awareness. The issue concludes with a bibliography of readings, organizations, and other sources of further information.*

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"I try not to think about Sarah having an apartment, being independent."

"My daughter is real slow, you know, and she wants to get a job. I know I should encourage her, but I can't sleep nights worrying about what might happen. Someone could easily take advantage of her. What if she were attacked, or worse—raped? There is so much bad out there. I pray that I will have the courage to do what is best for her."

"From the things I've read and the people with disabilities I've talked to, the one thing that stands out is that their parents or teachers expected them to succeed and did not treat them as if they had a disability. I try to do this for my daughter."

"The idea of Marsha riding the bus scares me to death. She's so small, what if she gets hurt?"

"Look, I know what I should do, but the bottom line is that this is my daughter. I don't think I can take the pain of always worrying about her. People are not always kind; she could be rejected, laughed at, or even hurt. She's my responsibility, and I don't take that lightly. I love her too much to ever have her hurt."

"My daughter is deaf. I don't want her riding the METRO alone. What if she needed help? People wouldn't be able to understand her. They might not even understand that her cry for help was a cry for help!"

The above are comments by parents of daughters with disabilities. They reflect the very real concerns of parents and the conflicts that all parents have between wanting their children to be independent and also wanting to shield them from possible pain. The urge to protect children is natural and normal. But protection can sometimes work against promoting maturity and self-reliance. All parents—whether their child has a disability or not—need to search for, and hopefully find, that area between too much and too little protection.

We are committed to helping all persons with disabilities eventually live as independently and with as much self-reliance as possible, but we know that independence, particularly for girls, is a troublesome issue. It does not happen overnight. Fostering a person's ability and desire to live independently must begin early and be a part of the daily consciousness of significant caregivers. Therefore, it must begin at home and continue to be fostered at school and by society in general. Becoming aware of the issues related to self-determination, which incorporates independence and self-sufficiency, and the factors that contribute to it, is an essential first step for families and professionals to take.

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Why is Independence So Important?

Our society was founded upon a belief in personal freedom, meaning that all of us have the right to make our own life choices about education, work, religion, relationships, and so forth. We also believe that a person should be given opportunities to succeed to the extent of his or her abilities and desires. People with disabilities have been long denied the rights of personal freedom and opportunity. Today, through research, education, and exposure to successful people with disabilities, we, as a nation, are realizing that individuals with disabilities have the same rights as the rest of society. They must be allowed to make personal choices. And with opportunities—the proper training and education, and guidance from families and service providers—we are seeing people with disabilities participating in the American dream of independence, personal fulfilment, and achievement. No longer do we hold up the lone achiever, the exceptions; we are beginning to expect it of all people with disabilities. "Remember that persons with disabilities are *persons* first and disabled individuals secondly. These persons have the same right to self-actualization as any others—at their own rate, in their own way, and by means of their own tools. Only *they* can suffer their nonbeing or find *their* 'selves.'" (Buscaglia, 1983, p. 18)

"Remember that persons with disabilities are <u>persons</u> first and disabled individuals secondly."

For boys and girls alike, developing independence is a natural rite of passage from youth to adulthood (Corbett, Froschl, Bregante, & Levy, 1983). Being independent creates positive self-esteem. But independence does not develop in a vacuum. People cannot make reasonable decisions without experience in decision-making—without testing themselves in the world, trying and failing, and trying and succeeding. People do not work if they have had no job training, or become economically self-sufficient if they have been channeled into a job which only minimally uses their capabilities and strengths. People may not aspire without knowing that others with disabilities like their own *have* aspired and achieved. And perhaps most importantly, individuals with a disability cannot achieve independence if *the expectation is that they won't or can't.*

Independence, however, does not necessarily mean that the individual must perform all tasks alone, without help from another human being. Few of us, in fact, could be called independent according to such a standard. For example, achieving independence may require transportation or basic living support, or other types of assistance and accommodation (Litvak, Zukas, & Heumann, 1987). With proper assistance, however, many people with disabilities are quite capable of supporting themselves, living outside the family home, developing enriching relationships, and becoming proud, productive contributors to society (Rousso, 1988). Others might not achieve total independence, but can look after and care for themselves to an extent unthought of ten years ago.

The process of developing a level of independence, the ability to make decisions and manage one's self, is life-long, with the foundations laid long before a person reaches adulthood. Thus, as concluded by Buscaglia (1983), the family's role becomes one of encouraging emerging individuality for special children, permitting them to make their own choices, and to exert and express themselves. In order to do this, the family will have to rid themselves of any preconceived notions of the child's dependence, limited abilities, and inferior family status and allow the child to reveal his or her own needs and abilities (p. 117).

The major issues addressed in this ***NEWS DIGEST*** are those of boys as well as girls, or men as well as women; however, we don't seem to be as successful in fostering independence and self-reliance in women as in men. Likewise, all the suggestions given would apply to boys as well as girls. For whatever reasons, however, we do not seem to be applying them to girls as frequently as to boys. With opportunities for and protections of the rights of all individuals with disabilities, we must ensure that these rights are extended to all women with disabilities to the same degree as to men. The issue of women and girls with disabilities and their right to self-determination is a complex one. The following statistics under-score the need for families and schools to work together to promote positive outcomes for this nation's women with disabilities.

Some Recent Research on Women and Men With Disabilities

The National Longitudinal Transition Study (Wagner & Shaver, 1989) conducted by SRI International examined several aspects of the employment experiences of young people with disabilities and found that males with disabilities out of school for two years were most likely to work as semi-skilled or unskilled laborers (26%) or in service occupations (27%). Women were most commonly employed in service (58%) or clerical jobs (21%). In addition, it was found that being male, older, white, and from a higher socioeconomic background were factors linked to a higher probability of competitive employment. Youth with higher functional abilities, those who had graduated from high school, and those who had participated in occupationally-specific vocational education and in work experience programs in high school also were significantly more likely than others to be employed after high school.

Hazasi and her colleagues (Hazasi, Johnson, Hazasi, Gordon, & Hull, 1989) have summarized some of the major studies that have followed-up special education students after they have left public school. Overall, these studies have found that, in the first year after school, males are more likely than females to be employed, to be employed full-time, and to remain employed full-time during the next two or three years, when the follow-up stopped. In addition, all of the women students with disabilities were employed in unskilled jobs. These outcomes were the same across different

studies, in different areas, with different employment opportunities.

Based on labor force statistics for the 1988 work year, 23% of the working age men with a disability had full-time jobs compared to 13% of working age women with a disability. The income of individuals with disabilities who worked, either full or part time, in the year 1987, showed similar disparities for men and women. The mean income for men with disabilities who worked in 1987 was $12,377, compared with $6,355 for women with disabilities (U.S. Bureau of the Census, 1989).

"Not working is perhaps the truest definition of what it means to be disabled," report Harris and Associates (1986, p. 4), following their survey of disabled Americans. Over 64% of all men with disabilities were totally out of the labor force in 1988; this compares to almost 73% of all women with disabilities (U.S. Bureau of the Census, 1989). Harris and Associates (1986) also report that the majority of those with disabilities and out of the labor force depend on either government benefits or insurance payments for their support, and 40% receive no benefits of any kind. The latter are mostly women who must depend on someone else for their support. Since a desirable outcome of the education experience is paid employment, these and other statistics on the employment of those with disabilities are very troubling.

Why the Differences? A Look at Society

Being a female and having a disability both have ramifications for the individual. In our society and in our schools, each of these descriptions engenders preconceived notions, expectations, and stereotypes. In both instances, it is the negative stereotypes that hold girls back or unnecessarily channel them into certain types of programs and jobs.

Although much has been written about parenting children with disabilities, few studies mention the gender of the children and still fewer suggest that gender makes a difference (Fine & Asch, 1988). Yet we know from research that, from the earliest moments of life, parents and others react to

> ***In my childhood I wanted to grow up to be able-bodied. I would be cured and never have polio again. Or, I wanted to be a boy. My father paid my brother for his chores but not me, even though I was older, because, "you're a girl and you're supposed to do housework." Boys could grow up to be important, even if they were disabled. There was Franklin Roosevelt, Beethoven, Ironsides, and all those athletes making miraculous recoveries. But there was no one I could be, except maybe Helen Keller. (O'Toole 1979)***

and treat boys differently than girls. In a now classic study, groups of people observed the behavior of a 15-day old infant on videotape. One group was told the infant was a boy, the other that it was a girl. Observers described the "boy" as more active and outgoing, while the "girl" was described as passive, crying, and in need of help (Condry & Condry, 1978).

Typically, boys are encouraged to be sturdy, to dare, to go out and meet the world. They are expected to become self-supporting, in anticipation of the day when they will have to support a family. Girls, on the other hand, being perceived as more passive, are sheltered. As the future "nurturers" of society, they are rewarded for their sensitivity to the needs of others and their ability to cooperate rather than aggressively pursue their own interests.

Differences in formal schooling emerge from how society views differences between males and females. For example, for the past century educators have assumed that boys learn to read more slowly than girls and are more prone to having reading disabilities such as dyslexia. In a recent *Newsweek* article (May 28, 1990), author Laura Shapiro reports that, in order to remedy these deficits, the schools employ a number of remedial reading teachers whose classes are filled primarily with boys. In contrast, girls have usually fallen behind in math by the time they reach high school. Yet, significantly fewer remedial math teachers are employed to help the girls during their elementary and junior high years when the problems are first identified. "Girls are supposed to be less good at math, so that difference is incorporated into the way we live" (p. 57). In an interesting counterpoint to this educational inequity, the findings of three recent studies refute the long-standing notion that boys are more prone to have dyslexia (Kolata, 1990). In one of the studies, conducted by Yale University, more than four times as many second-grade boys as girls were diagnosed by the school system as being dyslexic, and more than twice as many third-grade boys as girls. The Yale University researchers, testing the same children independently, found that equal numbers of boys and girls had reading difficulties. Dr. Sally Shaywitz, the co-director of the Center for the Study of Learning and Attention Disorders at Yale, says, "Girls, who really need help, are failing to be noticed" (Kolata, 1990, p. B6).

How do stereotypes of male and female behavior and potential affect children with disabilities? To begin with, many adults feel that children with disabilities need more help. Boys with disabilities can often escape the disability stereotype of helplessness or dependence by aspiring to such traditional male characteristics as competence, autonomy, and work. Girls with disabilities, however, confront two stereotypes—the "passive, dependent" female and the "helpless and dependent" person with a disability. As a result, they often get a double dose of assistance that can lead to a kind of a dependence called *learned helplessness* (Lang, 1982).

There is no doubting that society bombards us, via television and magazines, with images of the "ideal" female. Probably the ideal most damaging psychologically to many people with disabilities is this society's emphasis on physical beauty or attractiveness. While thousands of dollars are spent on cosmetics, physical fitness, clothes and hair-stylists, most of us fall far short of the ideal. Yet, we all strive for it. However, the gap between the ideal and reality varies from person to person, and many women with disabilities are affected more negatively.

Images showing motherhood and homemaking are also very powerful, and it is normal for parents and their daughter

with a disability to identify with these roles. These are certainly very important roles in our society. Yet, young women with disabilities are less likely than their nondisabled peers to take on the traditional role of wife (Bowe, 1983) and even less likely to have the role of mother. When young girls and women are not encouraged to be independent and achieve some level of economic sufficiency, and believe or know that the options of wife and mother are closed to them, they are denied a meaningful role in adult life—a situation that results in *rolelessness* (Fine & Asch, 1988). The lack of having a part to play in life produces low self-esteem and a lack of confidence in one's self and one's activities and ideas. This can and does cause further dependence for the roleless person, most often on the parents and then on whomever later assumes the role of caretaker.

Today, in our society, single women who live alone and work are accorded more freedoms and respect than ever before. This is not an uncommon situation for a woman to be in, and many are successful in their work, self-sufficient, and prefer their independence. A woman in our society no longer has to derive her status from her husband. This is an important concept for a young woman with disabilities and her family to understand; women with disabilities who work and do not marry can find peers—both disabled and nondisabled—in similar situations. For those who choose otherwise, there are growing numbers of women with disabilities successfully married and with children who can serve as role models. What is important to understand here is that women with disabilities have the same options and choices for a lifestyle, and to be happy in that life style, as do women without disabilities.

While the above is true, we still have stereotypes, and young women with disabilities who receive vocational guidance and training are not exempt from society's pervasive ideas of what a male and female can and should do. Kratovil and Bailey (1986) summarize a number of studies that found that women with a disability, some receiving vocational counseling, others participating in workstudy programs or receiving vocational rehabilitation training, tend to be given guidance or instruction that tracks them into jobs consistent with traditional sex-role stereotypes. Such jobs tend to be service-oriented, lower paying, lower skilled, and generally less interesting. Female special education students rarely have access to courses in business, for example, which could lead to higher paying jobs. On the other hand, males with disabilities are placed in programs that provide training in a specific trade and also have many more opportunities for actual job training experiences. Moreover, they are trained for higher paying jobs that offer chances for advancement.

> ***I never knew what would happen to me when I left school. It scared me. I used to believe that when I graduated I'd die or live with my family forever. That was because I'd never met a deaf woman. (O'Toole 1979)***

Women who are not disabled intellectually also have a difficult time. There is still a tendency on the part of people who are uninformed about disabilities to see a person with a physical disability and immediately assume that he or she is also less cognitively capable. Much can be done to change this assumption, and other negative ones, through awareness training and the modeling of successful women with disabilities. Change begins, however, within the family and woman with a disability. Families need to believe that their daughter with a disability can achieve, and work to instill that belief in her during her earliest days.

Differences in vocational training, as well as the very low rate of females with disabilities who are in some type of post-secondary education program, clearly suggest gender bias and a lack of positive self-assertion on the part of the women with disabilities. Hasazi et. al. (1989), who point out that research with nondisabled youth also shows less positive employment outcomes for women, suggest that there are several factors involved, including discrimination in the work place. They also point to the tendency of women not to consider security and advancement aspirations and to have less self-confidence than males when it comes to seeking jobs.

"The severe disadvantage disabled women and girls suffer is revealed in the economic and social realities they ultimately face," state Kratovil and Bailey (1986). "After 12 years of public education, disabled women all too often find themselves ill-equipped to do anything but remain in the family home or be institutionalized" (p. 251). They conclude that "the plight of the disabled woman, striving to realize her maximum potential as a productive, self-sufficient individual, results in large part from a widespread attitude that although the disabled man must become self-supporting, the disabled woman will somehow be cared for and protected" (p. 252).

What Can a Parent Do? A Look Within

There is no single or simple reason why these gender differences exist in our society. Yet they do exist. "Parents may wonder if gender roles are immutable... But burgeoning research indicates otherwise. No matter how stubborn the stereotype, individuals can challenge it; and they will if they're encouraged to try. Fathers and mothers should be relieved to hear that they do make a difference" (Shapiro, 1990, p. 56).

The difference parents can make begins with examining their own values and attitudes regarding male and female roles. Parents may consciously or unconsciously have different expectations for their daughter and may not encourage as much independence and achievement as they have for sons. There is some research evidence, for example, that parents of females with mental retardation are less likely to encourage and expect self-sufficiency and community living than parents of males with mental retardation (Burchard, Hasazi, Gordon, Rosen, & Dietzel, 1986). It can be assumed that this comes from their normal fears for their daughter's safety. There is no doubt that families have difficult decisions to make in this regard. They must decide their actions by considering the options and the consequences of dependency, and realize that parents will not always be around to protect and be social companions for their daughters with disabilities. Parents need only recall the statistics presented earlier to know that their lower expectations can inadvertently lead to the consequences of dependency, unemployment, and poverty.

Thus, it is imperative that parents of a

daughter with a disability look within themselves and become aware of how gender bias enters into the decisions they make—and allow others to make—for their daughter. They cannot ignore the future or expect it to take care of itself. The responsibility for planning and preparing for their daughter's future as an independent and self-sufficient person is primarily *theirs*, while the ultimate decision of how she will live and where she will work is primarily *hers*.

Steps Towards Independence: Beginning at Home

What can parents do, in practical terms, to foster greater independence and self-sufficiency in their child? Perhaps the single, most important thing parents can do to help their child is to expect her to *aspire*. If parents truly want their daughter to realize her potential for independence, they must make this their expectation from day one. From infancy on, they should allow her as much autonomy as possible, stretching her vision rather than limiting it. She should be encouraged to go out and meet the world. This is a common thread running through the stories of women with disabilities who have strived for and gained independence and self-sufficiency—their parents expected and encouraged them to aspire and achieve (Harrison & Rousso, 1989).

Here are some ideas that parents can put to use in their home and in their parenting style.

➥ **Start early.** Don't wait until your daughter is sixteen. Independence and self-determination are built one day at a time. Encouraging a child's learning, growth, and achievement should be a part of the daily consciousness and activities of the household.

➥ **Recognize that *your* behavior, as a family, may need to change.** It may need to change because you have come from a different culture with societal expectations that place limitations on women's achievement and self-determination. Or perhaps change is indicated because you do not know, or have not considered, the options available to your daughter in today's society due to new education programs and work opportunities.

➥ **Take a personal assessment.** Identify the expectations you have, the assistance you routinely offer your daughter, and the motivation she has or is given to develop her capabilities. For example, if she is in a family with all female siblings, do you expect as much from your daughter with a disability? If she is in a family with male siblings, how are your expectations for her different? Families need to have the same expectations for their female and male children, and provide their daughters with the same opportunities they would give a male child with the same disabilities.

"Perhaps the single, most important thing parents can do to help their child is to expect her to <u>aspire</u>."

The following suggestions are limited by the great variety of disabilities to be addressed. Probably the most beneficial advice is to really assess your daughter's abilities, and examine your thoughts about what you expect of your other children and of her. Think of ways she can become a more integral and contributing member of the family.

Expectations. How much do you expect your daughter to do for herself? Take a look at your girl's day: Where can you expect her to do more for herself? Where can you expect her to do more within the household? Eve expects her daughter, Carol, who has a physical disability, to be a fully contributing member of the family. Duties and roles are assigned to 11 year-old Carol, with consideration of her disability, but neither the task nor the expectation that it be done each week or day—and done well—are any less than for Eve's other children. Eve strongly believes that the more you expect from your children, the more you'll get. Carol presently is responsible for vacuuming the downstairs carpet and upholstery; she can do this from her wheelchair. Carol is also responsible for dusting the downstairs furniture and, of course, for keeping her own room tidy. Carol cleans every Saturday morning with the rest of her family.

Assistance. How much assistance do you offer your daughter? To achieve greater independence, she has to do things without constant help, reminders, and suggestions. And she *can* do these things, although it may take longer and be more difficult than if you do it for her. Your daughter may even tell you so, as Felicia, age 10, told her mother. Felicia, severely disabled by cerebral palsy, but with no cognitive disabilities, struggled to extract a pair of "cool" sunglasses from the small purse she carried. She fended off her mother's attempts to assist her, saying, "Mommy, I can do it, I can do it." While it was painful for the mother to watch the effort and the time it took Felicia to unzip her purse and extract the prized glasses, the mother forced herself to let Felicia accomplish her goal without help. This small task is only part of the family's ongoing efforts to allow Felicia to develop independence. Among other things, they have provided her with a motorized wheelchair, customized to compensate for her particular difficulties, and a communication board, both of which Felicia has mastered.

Many caregivers speak of the pain of watching their child's laborious efforts to perform what, to most of society, are routine tasks. And while it is natural to want to step in and help, and to spare your child the struggle, it is often better to let her do the task in her own time and in her own way. Then the achievement is hers. So, look closely at the assistance you give, and decide when and how it can be faded over time. Parents too must let go at their own pace and in their own way—no one would say that letting go of any child is an easy task. It may involve taking risks that you find disquieting. One mother, Joan, told of her personal compromise in letting her daughter with mental retardation, age 15, ride the bus alone. Joan was afraid for her daughter's safety. After discussing her concerns, Joan and her daughter agreed that Joan would shadow her by following the bus in her car for the first month that her daughter rode solo. Joan observed the people who waited with her daughter at the bus stop, asking herself if any might be suspicious. She watched her daughter's interactions with the people and observed where her daughter sat on the bus. (Joan had told her daughter to sit directly behind the bus

driver.) At home, Joan would discuss with her daughter "make believe" situations based on her observations. In this way, she could give her daughter suggestions on how to act, or what to do.

Roxanne, whose nine year old daughter has a learning disability, reported following her as she walked through a housing project alone to her after-school program. Roxanne hid behind trees and buildings so as not to be seen. She did this to assess her child's ability to make judgements in life situations, to avoid situations of potential danger, and to get to her destination without getting lost and in a timely manner.

Motivation. Your daughter may very well want no part of being self-sufficient. It's much more convenient to have you! So you need to develop a system of rewards, such as attention, praise, tokens, or permitting her to do something she likes once the task has been completed successfully. Focus on her positive behaviors and reinforce these.

Another vital component of independence is decision-making. How do parents teach this complex skill? First, consider how it feels when you are told what to do, instead of being allowed to act according to your own preferences and judgement. Also, ponder how you learned to make decisions and how you taught your nondisabled children to be good decision-makers. As much as possible, apply the same methods to your daughter with a disability.

The reasons we make decisions, of course, cover a spectrum of daily and life choices. Knowing when to put on a jacket is a decision that a child who is deaf will not long find difficult; it may be a much more complex decision for a child with severe disabilities to make. Much modelling and repetition may be necessary to help such a child learn to make decisions herself. Howard, whose five year old daughter has a number of severe disabilities, recounts the process by which he taught Jana to recognize when a jacket was needed, to get the jacket, and to put it on herself. "I would just do it myself, at first, getting her the jacket and putting it on her. Then I started telling her to get the jacket. Then, for a long time we worked methodically on her putting on the jacket by herself. After she could do that, I started saying, 'Gee, it's cold today. What do you need to put on, if you're going outside?' It took a long time before she knew the answer, but she was so proud of herself, it was worth the time."

For children who have difficulty in learning to perform a task from beginning to end, you may need to break the task into its component parts and teach each part separately. Then, when your daughter can successfully perform each part, expect her to begin combining the parts. Foster her ability to make these decisions about sequence by asking her, "What's next?" Through your modelling and repetition, she will learn to ask herself "What's next?" Eventually she will be able to perform the task herself, from start to finish.

"For parents, allowing their much-loved child to take risks is disquieting, even more so when that child is a daughter."

An essential part of good decision-making is *self-awareness*. Having insight into what your daughter's strengths and weaknesses are, given her disability and her motivation, will help you to help her in all facets of her life. Her ability, through your help, to assess herself—how she feels, what she believes about herself and others, what she wants in life—provides a central point around which to make decisions. Realism, of course, is important in self-appraisal. You can foster your daughter's self-awareness and her ability to make honest self-appraisals by being honest yourself, by allowing her to make decisions that require her to identify her preferences and desires, and by engaging her in conversations that lead her to examine herself. It is especially important that your daughter realize her strengths and learn to emphasize them. For example, Debbie, a mother of a six year old daughter with mild retardation, cranial disfigurement, and a speech impediment, replies to her daughter's statements of "I can't do that" by emphasizing what she can do. "Well, maybe now you do have a difficult time doing that, but let's look at what you could do," replies Debbie. Then Debbie proceeds to discuss with her daughter what she can do in that particular instance. Debbie believes it is most important to turn every "I can't" into a conversation of what "I can do."

Rita, whose teenage daughter, Beth, has a learning disability, often talks with her after school about how Beth's day has gone. At times, Rita's questions are quite probing: "Why did you do that?" "How did that make you feel?" "Are you sure you can't do that? Tell me why you think you can't." "Is it because you think you can't do it, or because you just don't want to?" Such questioning serves to make Beth examine her thoughts, feelings, beliefs, and capabilities. These discussions also confirm for Beth the importance and validity of her opinions and give both mother and daughter a greater awareness of what it means to be Beth.

Another intrinsic part of decision-making is the ability to consider consequences (Clabby & Elias, 1986). Depending on your daughter's disability, this may be more or less difficult. José's daughter, who is eight and has been blind since birth, is easily frustrated and loses her temper frequently. When Paula has behaved badly at school, José reinforces the teacher's remarks to Paula by demonstrating the consequences of socially unacceptable behavior. Paula is not allowed to phone her friends or have anyone over after school. The consequence of poor behavior is social isolation. Gaye also discusses the consequences of decisions with her teenage daughter who uses a wheelchair. She doesn't tell her daughter what to do; rather, she asks her what options are available, what each option involves in terms of reward and consequence, and, perhaps most importantly, how she feels about each option (requiring that self-awareness discussed above). Based upon the factors involved, her daughter reaches her own decision. Through asking questions and exploring alternatives, Gaye models for her daughter an effective process for making decisions.

Sometimes, making decisions and acting upon them involves taking physical, emotional, or intellectual risks. For parents, allowing their much loved child to take risks is disquieting, even more so when that child is a daughter. "She might get hurt," "She can't protect herself," and "I can't stand to watch her try and fail," are reasons parents of girls commonly give for

wanting their daughter to go slow, be careful, and hold back. The problem is, girls then *learn* to hold back and will "play it safe" in the kinds of decisions they make. This results in self-limiting thinking and behavior.

Teaching your daughter that it's okay to take risks may mean that you have to teach yourself as well, gritting your teeth and crossing your fingers as Roy did when his daughter, a seven year old with a hearing impairment, began negotiating their community alone. "I don't know who was more scared, Helen or me," Roy says. "But she really wanted to try on her own, and I knew it was the only way for her to learn. So I thought, 'Okay, Lord, watch over her.' " Roy laughs. "I have to admit that sometimes I still follow her, just to make sure she's okay." It is, never the less, important for parents to be honest about their concerns and to share them with their daughter. This will help you to confront your concerns and to develop trust in your relationship with your daughter.

Mariá, whose 18 year old daughter has a physical disability, with speech and visual problems, needed to come home from a jobsite by public transportation. The first day, as the family anxiously awaited her return, she did not. The police were finally called, but Leticia returned home on her own as the police reached the house. As it turned out, Leticia had missed her stop, even though her parents had traveled the route with her beforehand, and had to negotiate her way back on her own. The family was quite upset and Mariá's first impulse was to say never again, but Tony, her husband, pointed out how very well Leticia had done on her own; she had shown that she could independently negotiate her way home—which, after all, was the point.

Teaching that it's okay to take a risk involves teaching that it's okay to try and fail. In fact, in learning a new skill, even the most adept person generally has many failures on the road to mastery. This is an important message to give your daughter. Understanding that learning may involve repeated attempts to do something before one is successful places initial failures in their proper context and illustrates that immediate success is not essential, but the willingness to try and try again *is*.

Encourage your daughter to try new things, even if this means she has to struggle and swallow initial failure. Be understanding, too, if she shows a range of emotional reactions. We all have felt the fear, frustration, anger, and occasional despair that can accompany trying something new and difficult. Your daughter is as entitled to these human reactions as any other person. Praise her attempts and honor the courage it takes her to keep on trying. Your encouragement will be a powerful validation of her effort and will reinforce the message that only in striving do we achieve.

In short, whether the decision is a small one, such as what to wear or what to eat, or a far-reaching one, such as what career track to follow, encourage your daughter to identify her preferences and act upon them, even if this means taking a chance and risking failure. In this way, she develops her sense of self and the ability to take action that expresses that self. The skills of decision-making are learned in many ways: modelling, discussion, risk-taking, consideration of consequence, and practice. The more decisions you allow her to make, the better equipped she will be to determine her own way in the world outside your home.

Developing a Social World

The teenage years are critical, exciting, stressful times for all young people—with or without a disability. As your daughter becomes a young woman, you will have many considerations and concerns about her maturing body and her interactions with the world outside your home. School places her in the midst of her peers and provides her with greater opportunities to socialize and discover a self that is separate from the supports of family. Some youth with disabilities may isolate themselves out of self-consciousness, uncertainty, or the fear that no one could really care for them. It's even more important at this time to urge your child gently to seek companions and become involved in events, such as recreation groups, church or extracurricular activities, arts and crafts, or day camps. Adolescents need these social opportunities to explore and develop friendships, to experiment with a variety of social roles, and to experience control over their own lives. Interaction with others with disabilities can be particularly beneficial. Finding that there are others like herself, with similar concerns, experiences, and feelings, can help to decrease the sense of isolation and "differentness" your daughter may feel. At the same time, these interactions provide her with an important support network.

The teenage years mark an adolescent's transition into adulthood physically as well as socially. The maturing of your daughter's body brings with it a new host of health concerns. She must learn how to care for and respect herself as a woman. This means your daughter will need:

- clear discussions about menstruation as a natural event of womanhood;
- information and training in how to care for herself in this regard; and
- regular visits to a gynecologist or family doctor.

The physical maturing of an adolescent's body is also accompanied by the emergence of sexuality. Many parents react to their adolescent's developing sexuality with alarm, and increase, rather than decrease, their vigilance. This is particularly true when the adolescent is female. Yet, when an adolescent female has a disability,

A Few Words from Harilyn Rousso

One of the myths in our society about disabled women is that we are asexual, incapable of leading socially and sexually fulfilling lives. When I was growing up, my parents and I accepted this myth without question. We simply assumed that because I had a disability, I could not date, find a partner, or have children. As a teenager and young adult, I put aside any hope of a social life and concentrated on my studies.

It never occurred to me that I had any alternative, that I could have both a career and a romantic life. Betty's lifestyle (another woman with a disability), her successful marriage to an interesting, dynamic man made me question for the first time the negative assumptions I had made about my social potential. She planted the seeds of positive possibilities... (Rousso, 1988, p. 2)

the increased protectiveness of her parents may be accompanied by a tendency to treat her as if she were asexual, still a little girl. This is a common theme in disabled women's literature (Browne, Connors, & Stern, 1985), in which many women with disabilities speak candidly of the difficulties, confusions, and low self-esteem that result from being treated as a nonsexual being when one's internal feelings are quite the opposite.

Thus, parents of a young women with a disability should give serious thought to the messages they send their adolescent daughter about her sexuality. "Some people assume that if you are disabled, you can't have a social life or a sex life. This reflects one's own fears that unless one looks terrific physically, he or she will not be wanted. This is very potent stuff" (Weiner, 1986, p. 72).

Many parents find it difficult to talk frankly with their children about issues of sexuality. This reflects their concern that, should their child's sexuality be acknowledged and nourished, she will be subjected to rejection, abuse, unwanted pregnancy, or veneral disease (Rousso, 1981). However, all adolescents, disabled or otherwise, need reliable information about love, sex, conception, contraception, and veneral disease, in order to prepare for their lives as independent, responsible adults (Buscaglia, 1983). Here are some suggestions for dealing with this stressful time in your daughter's—and your—life.

➥ Realize that your daughter's physical development will be accompanied by the same sexual feelings and needs that all adolescents feel. You have no more control over the emergence of these feelings than she does.

➥ Don't restrict your daughter's social activities, in the hope that this will negate her sexuality. Restricting her in this way only deprives her of vital physical and mental stimulation.

➥ Be aware that, legally, you will not be your child's guardian forever. This is true no matter the severity of the disability. Although state laws vary, in most states a parent's guardianship, or legal authority over their child, ends when the child is 18.

➥ Sterilization is a difficult subject and a personal choice. Laws vary from state to state, so be aware of them. Most states have followed a recent trend prohibiting involuntary sterilization of individuals, meaning that your daughter must consent to it.

➥ Information and openness regarding sexuality are important for healthy development. Talk about, teach about, and counsel on issues of sexuality and the responsibilities that accompany sexuality. If this is difficult for you, find help—counselors, clergy, parent support groups, Planned Parenthood, and other adults with disabilities are good sources of information.

➥ Have open discussions about sexuality and disability with your daughter Acknowledge the social realities and the fears and uncertainties about their bodies and sexuality that many women with disabilities have. Issues of sexuality and disability *are* complex. But also be reassuring that it is possible to find loving partners—many women with disabilities have successful, intimate relationships and children.

➥ Expose your daughter to positive role models of women with disabilities. Expose her to those who have mature, loving relationships, and family lives. Discuss what is involved in building such relationships. Expose her to women who live alone and who are successful, independent, and self-sufficient.

Yes, it's scary to admit that your daughter has sexuality. Frankly, it is difficult for most parents to accept and deal with this in all children, whether or not they have a disability. But "...remember that the disabled have the same needs that you have, to love and be loved, to learn, to share, to grow and to experience, in the same world you live in..." (Buscaglia, 1983, p. 18).

Confronting the World of School and Work

Three federal laws require the provision of sex equitable education to students with disabilities. These laws are Title IX of the Education Amendments of 1972, Section 504 of the Rehabilitation Act of 1973, and Public Law 94-142, the Education for All Handicapped Children Act. On the basis of these laws, your daughter cannot be denied special education, related services, or vocational education. (You can obtain more information about these laws by contacting ***NICHCY***.)

Our educational system can represent one of the greatest vehicles for self-empowerment that your daughter has at her disposal, because, through schooling, she can equip herself with the knowledge and skills needed to achieve independence and self-sufficiency. As has been discussed, however, inequities can occur in the provision of services, due to expectations regarding the roles of males and females in society in general and, more specifically, the capabilities of a female with a disability. Therefore, parents must be committed to securing the best, most appropriate education for their daughter, and vigilant that she does not receive guidance or instruction that unnecessarily limits her development along sex-biased and stereotyped lines.

Here are some suggestions for working within the educational system to ensure that your daughter receives an education that develops her intellectual, social, and physical capabilities without limiting her future.

➥ **Be involved.** Talk to your child's teachers and other school personnel. Make the effort to be present at all meetings to discuss IEPs developed for your daughter, and share any special concerns, ambitions, or disagreements that you have. Remember, *you* are experts, too; you know a great deal about your child, and are an important member of the team. Let them know that you expect her to achieve, and work with the school, especially her counselors and teachers, to make sure she is in programs that foster this.

➥ **Be aware.** Find out what your daughter is learning in class and how you can support this learning at home.

➥ **Be supportive.** Let your daughter be involved in extracurricular activities. Social contact with peers is a vital part of growing up and learning to be independent.

➥ **Be knowledgeable.** Know your rights and the opportunities available in the school and county. Work with the school system to assure that an appropriate education and services are being provided for your daughter, taking into consideration both her needs and her ambitions. For example, if she plans to go to college, make sure she takes the required courses for entrance; if she needs job training, make sure vocational training is in her IEP. Counselors are a good resource and are available for consultation regarding tests, applications, and services after high school.

➥ **Be an advocate.** If you detect a problem in the provision of services, confront it. "It's amazing how people respond to you when you are prepared, committed to listening, not attacking them, and determined to get what you feel your child needs" (Weiner, 1986, p. 109). Talk with other parents of children with disabilities. By combining your forces, when and where necessary, you can effect change in your school system and community regarding sexual stereotyping and awareness.

As your child matures, the world of work becomes an increasing concern. Regardless of the nature of your daughter's disability, actively pursue employment as a goal for her. Do not think this is unreasonable. Gay Tompkins, a teacher in Arlington County, Virginia, who teaches children with disabilities ranging from mild to quite severe, reports that, in her program, "We expect every child, no matter how disabled, to have a job someday." This is true in classrooms across the nation. For some, attaining this goal may require support and appropriate accommodation, an approach known as partial participation, partial assistance. For all, however, securing the goal of employment requires the expectation and involvement of significant caregivers. "Work makes a vast qualitative difference in the lives of disabled Americans," report Harris and Associates (1987, p. 2). "Comparisons between working and nonworking disabled people show that those who work are more satisfied with life, much less likely to consider themselves disabled, and much less likely to say that their disability has prevented them from reaching their full abilities as a person" (Harris and Associates, 1987, p. 2).

In determining a career path for your daughter to follow, you may need to set aside certain work or status expectations you have for your daughter and examine the ideas you hold about what is acceptable work. A statement such as "I'm not going to let her go into social work. She's going to study computers, that's where the future is!" reveals what parents want for their child, and denies what the child may want for herself. Similarly, proclamations such as "Fold laundry? Not my child! She'll stay at home with us first!" reflect the belief that certain types of work are unacceptable. Before parents can summarily reject a type of work as inappropriate for their child, a realistic assessment of the child's strengths and weaknesses must be made. Moreover, each child is an individual with her own personality, preferences, and desires. What she *can* do and what she *wants* to do should be the primary considerations for determining what she will do, not whether the parents feel a certain type of employment measures up to their expectations or is "acceptable" for their child.

Career planning is typically developed in conjunction with the school system.

The Importance of Role Models

When Harilyn Rousso, who has cerebral palsy, was growing up, she had virtually no contact with other disabled people.

> I attended a regular school, so I just didn't know anyone else who was disabled... it never occurred to me that there could be very interesting, smart, attractive, witty, and successful disabled people. (Brozan, 1984, p. C1)

Then, when Harilyn Rousso was 22 years old, she met a female economist who also had cerebral palsy. "That association had a profound effect on me," she said. "I saw that she could make it in a man's field. But I was even more impressed that she was married... That woman made me challenge my assumptions about myself" (Brozan, 1984, p. C1, C11).

What happened to Harilyn Rousso illustrates how important it is that our children with disabilities are exposed to positive *role models*—others with disabilities who have successfully challenged the stereotypes of disability and their own limitations. Role models can be actual people—teachers, family members, workers in the community. Or they can be images that appear in books, posters, games, and the media. Seeing adults functioning in a wide variety of roles lets all children, and particularly those with disabilities, know that it is possible to grow up, work, love, parent, and lead independent lives.

Families and professionals learn just as much from being around people with disabilities. Mike, whose daughter was deaf, was very protective and openly stated that he did not believe his daughter would ever be on her own. Luckily for his daughter, a woman who is deaf was hired to work in his office. Mike saw how competent and self-sufficient she was. This experience completely altered his expectations for his daughter. He is now his daughter's greatest advocate for her independence and self-sufficiency.

Until recently, there has been an almost total absence of positive role models for girls and women with disabilities. This has had a profound effect on their self-image and sense of future. As one woman who is deaf states, "I used to believe that when I graduated I'd die or live with my family forever. That was because I'd never met a deaf woman" (O'Toole, 1979). Luckily, due to the pioneering efforts of women such as Harilyn Rousso, there are many resources currently emerging on video, in print, and in the form of organizations, that offer girls and women with disabilities the opportunity to learn what others like themselves have experienced and achieved.

As a parent, you can build your daughter's self-esteem and sense of her own possibilities by exposing her to positive role models of women with disabilities. Here are some suggestions for action:

- From early childhood onward, seek out women with disabilities in your community who are working, raising families, and doing all the things that women do. These women are no longer invisible. Invite them to your child's school, or arrange for your daughter to meet with these women and talk. At the very least, point them out to your daughter.
- Acquaint your child with the world of work. When friends visit, tell your daughter what type of job he or she has. Ask your daughter if she would like to ask your friend about what the job entails. Do this in a way that conveys that many career paths are open to her.
- Be sure that the school or program your daughter attends has a good selection of learning materials that represent people with disabilities in positive ways. Check to see that they are not presented in stereotypical female and male roles. Also make sure that they represent diverse racial and ethnic groups. Become active in helping your child's teacher locate resources. The latter is most important, for you can be a tremendous asset to your child's teacher in this area.
- Find the resources listed at the end of this ***NEWS DIGEST*** and share them with your daughter. These—and other resources such as your local library, independent living centers, and disability rights organizations—will expose your daughter (and you, too!) to books, plays, films, and television programs that portray positive images of people with disabilities. They will also help your child explore her options for education, independence, sexuality, work, and family life by providing role models of other women with disabilities who have successfully addressed these issues in their own lives.

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"Rather than seeing the person as unemployable because he or she has a mobility impairment and uses a wheelchair, society has become aware that the deficit... exists in the architecture of buildings which does not permit the person to enter."

Whether your daughter is placed in a vocational training program or pursues academic training is a decision reached through discussion with teachers, counselors, therapists, and you, the parent. Don't allow your daughter to have false limits set for her because she is a female or because she has a disability. Don't *you* set false limits, either. As Mitchell (1982) states, "The biggest career development problem for children with disabilities is the low expectation society (school, government, family) has for adults with disabilities" (p. 57).

Receiving training, vocational or academic, is essential if your daughter is going to achieve any measure of independence and self-sufficiency. Parents should be deeply involved in the process of planning what training their daughter will receive. Here are some suggestions for confronting the complexities of career development.

➥ Know what type of career training your school system is planning to give your daughter. Go to all meetings where this is discussed. Find out whether their plan has taken into account what her interests and potential are. If not, insist that an assessment of her interests and aptitudes be made.

➥ Don't let doors be closed to your daughter. Protect her, when appropriate, from the "norms" of the educational system, which, for her, may be a trap. For example, Claire knew that because of her daughter's learning disability she did not do well on tests and that it would be difficult for her to score well on the SATs even though there are provisions for time extensions for people with disabilities. Thus, she did not allow her daughter to take these exams, recognizing that to do so might close college doors to her and have an adverse effect on her self-esteem. Believing that her daughter could succeed in college, she enrolled her daughter in a junior college that did not require SAT scores for admission, thereby letting Sue prove that she could do the academic work despite her disability. Now, Sue is entering her senior year at a major university and will graduate with a degree in human ecology.

➥ Know what types of vocational and academic training are available and your daughter's rights to receive this training. (Contact ***NICHCY*** for more information.)

➥ Teach your daughter to be an advocate for herself. In order to be able to do this, the young woman must be self-aware, confident, and know how to set limits. This must be worked on in the home and at school. If possible, let her attend seminars, workshops, and classes where she can learn how to present herself to prospective employers. She also needs to know the fundamentals of effective communication. She should be able to communicate her capabilities, disabilities, and what types of accommodations her disability requires. Mary Beth, who is 20, has a learning disability. She learned during her first year in a junior college to be candid with teachers, counselors, and friends regarding her disability. She is now transferring that skill to job interviews. She tries to be clear about what she does well, what she cannot do, and what she can do with a little extra time.

➥ Discuss with school professionals how many males and females are in various vocational programs and discuss the variety of options available to your daughter and how she might gain access to the programs. Don't be put off by comments such as "most of our girls go into..." or "...is a good job for a girl." Ask about job training opportunities and job placement and ask if the school has information on its graduates, in term of employment, wages, and benefits. Do this early in her high school program.

➥ What does your daughter want? Defend her right to pursue her own goals! This may mean that you, too, must go against your own wishes, as Suzanne, the mother of a 24 year old daughter with autism, had to do. Suzanne wanted her daughter, Valerie, to enter a computer training program. Although Valerie was tested as able to do the necessary computer work, she was intent on having a job folding laundry. After much discussion, Suzanne accepted Valerie's decision. This is the essence of allowing one's child to be self-determining. Suzanne realized that there was a good probability that once she has gained confidence in her ability to work, she might want to enter a new field.

➥ Don't let another person's ideas of what is "realistic" for your daughter be *your* ideas. As Mitchell (1982) says, "Telling any minority group to be realistic is telling them to buy the prejudices of our society" (p. 69). There are quite a few women with disabilities who ignored the advice of guidance counselors to be "realistic and adjust" to their handicap and who have gone on to become successful scientists, lawyers, and social activists. Phyllis Rubenfeld is one such individual. Told by the Office of Vocational Rehabilitation that they would not sponsor her training in social work because her physical disability did not allow her to jump, she pressed for her rights to pursue her own career preference and won. Today she has a doctorate in education (Weiner, 1986).

➥ Bring your daughter in contact with other women with disabilities who can serve as role models. This may have to be through the media of print or video, if you cannot provide in-person meetings. (Some resources for this type of information are listed at the end of this ***NEWS DIGEST***.)

There have been many changes in recent years that are forcing society to re-evaluate the way it views the work potential of people with disabilities. For example, rather than seeing the person as unemployable because he or she has a mobility impairment and uses a wheelchair, society has become aware that the deficit, in fact, exists in the *architecture* of buildings which does not permit the person to enter. Federal law, including the recently passed Americans with Disabilities Act of 1990, requires employers who receive federal funds to make "reasonable accommodations" for a person with a disability. New technologies, such as sound-activated computers, are enhancing the work possibilities for persons with all types of disabilities (President's Committee on Employment of the Handicapped,

1986). Individuals committed to improving the status and opportunities of persons with severe disabilities have developed possibilities for *supported employment*, which emphasizes a "place and train" approach, rather than the "train and place" sequence used in vocational programs (Gardner, Chapman, Donaldson, & Jacobson, 1988). All these changes expand the horizon of job possibilities for your daughter, no matter the severity of her disability.

Summary

The seeds of future independence, self-sufficiency, and productive employment are planted at home with the messages you give, consciously or unconsciously, to your daughter from the time she is born. As she grows, encourage her to achieve whatever she is capable of achieving. Teach her to value her own ideas, desires, and preferences. Solicit her input. Give her responsibilities in the house and teach her how to execute them. Also let her know that she, too, belongs in the world that exists outside of your door—the social world where people talk to and care about one another, and the world of work, which people begin preparing for in a myriad of ways long before they are actually employed. Does she believe that the social and work worlds are waiting for her? Tell her that they are. Prepare her for these worlds and her own place in them by encouraging her to take risks and to make decisions for herself. Help her to develop skills that will permit her to function in the work world and the community. Be her advocate in school matters and in career planning, and teach her to be her own advocate. And show her that other women with disabilities of all sorts have achieved their own independence, emotional well-being, and economic self-sufficiency through aspiring to develop the capabilities they have and not letting others limit their own sense of possibility. There is no denying that your attitudes and your expectations today and along the way will powerfully influence her own attitudes and expectations and, ultimately, her achievements.

FYI: Information Resources

Bibliographic Note:

You can obtain many of the documents listed below through your local public library. Whenever possible, we have included the publisher's address or some other source in case the publication is not available in your area. The organizations listed are only a few of the many that provide various services and information programs about girls and women with disabilities for families and professionals. Additional support is also available from state and local parent groups, as well as from state and local affiliates of many major disability organizations. Please note that these addresses are subject to change without prior notice. If you experience difficulty in locating these documents or organizations, or if you would like additional assistance, please contact ***NICHCY***.

If you know of a group which is providing information about girls and women with disabilities, or developing materials and programs in your area, please send this information to ***NICHCY*** for our resource collection. We will appreciate this information and will share it with other families and professionals who request it.

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An increasing number of women with disabilities are becoming more vocal within both the disability rights and women's movements. This activism is reflected in many of the listings provided in this bibliography, as well as in the references cited throughout this ***NEWS DIGEST***.

The growth in resources for, by, and about women with disabilities is heartening for parents and professionals, but, most of all, for women and girls who see themselves reflected in literature and research.

The following resources are selective. They reflect the experiences and perspectives of women and girls with disabilities. Included are books for children, books for older readers, educational materials for parents and professional, videos and films, and organizations that address many of the issues discussed in this ***NEWS DIGEST***. The cited references are also recommended reading to add to your knowledge about women and disability.

CHILDREN'S BOOKS

Greenfield, Eloise, illustrated by George Ford. (1980). *Darlene*. New York: Methuen.

In this book a young girl named Darlene, who uses a wheelchair, is feeling homesick while spending a morning with her uncle and cousin. Darlene resists her cousin's attempts to play with her, but finally becomes absorbed in games and in her uncle's guitar playing. In typical fashion, when Darlene's mother arrives, Darlene doesn't want to go home. *Darlene* is outstanding because the child's disability is secondary to the plot; it shows a positive view of a Black family, and has a male caregiver as a main character. (Appropriate for grade pre-K to 2.)

Head, Barry & Seguin, Jim, designed by Frank Dastolfo, photographed by Walter Seng. (1975). *Who am I?* Northbrook, IL: Hubbard.

This book shows a girl who is hearing impaired playing, loving her family, and learning. The words "Who am I?" are the only ones in the book, and they appear periodically. The full color photo illustrations are nonsexist, multiracial, and inclusive. The book is part of the "I Am, I Can, I Will" set of materials created by Mr. Rogers but is available separately. (Appropriate for grades Pre-K to 4.)

Henriod, Lorraine, illustrated by Christa Chevalier. (1982). *Grandma's wheelchair*. Chicago: Albert Whitman and Co.

A book about the fond relationship between grandma and her four-year-old grandson, Thomas. Grandma uses a wheelchair, and Thomas spends time riding in her lap while they do things together. Grandma is depicted as a capable homemaker, taking an active role in the running of her house. Information regarding wheelchair use is integral to the story. (Appropriate for grades Pre-K to 1.)

Sargent, Susan Wirt & Donna Aaron, illustrated by Allan Eitzen. (1983). *My favorite place*. Nashville, TN: Abingdon Press.

This story is full of the multisensory experiences of a child's trip to the ocean. It is not until the end that the reader finds out that the girl in the story is blind. *My Favorite Place* helps young children understand the use of the senses other than vision—hearing, touch, smell, and taste. The child is shown actively swimming in the ocean and running from the waves. (Appropriate for grades Pre-K to 1.)

BOOKS FOR OLDER READERS

Garrigue, Sheila. (1978). *Between friends*. New York: Bradbury Press.

Sixth-grader Jill moves into her new neighborhood in August when most of the neighborhood children are still away. Only Dede is at home, but Dede is "different." She has Down Syndrome. Dede has a dog, and Jill is taking care of a neighbor's dog. The two girls walk the dogs together, and their friendship blossoms until the rest of the neighborhood girls return from vacation. Then Jill has to make some important decisions about how to maintain her friendship with Dede as well as build friendships with the other children. Jill learns that loyalty and caring are what make a friendship grow. (Appropriate for grades 3-6.)

Greenfield, Eloise & Revis, Alesia, illustrated by George Ford, photographs by Sandra Turner Bond. (1981). *Alesia*. New York: Philomel Books/Putnam.

This is a story of a young Black woman who becomes mobility impaired as a result of an accident. She is portrayed as a whole person with varied interests and feelings. The pictures and photographs reflect many of Alesia's friends and activities, and her family is supportive and caring. It is rare to find truly positive literature about an individual who is disabled and even more rare to find such works about a person of color who is disabled. *Alesia* is such a rare find. (Appropriate for grades 5 and up.)

Kent, Deborah. (1978). *Belonging*. New York: Dial Press. (Available in braille and as a talking book from the National Library Service for the Blind and Physically Handicapped, The Library of Congress, Washington, D.C. 20542. Telephone: (202) 707-5100.)

In this story, a girl who is blind is the first and only student with a disability in a suburban high school. This book has been a favorite with many adolescents and adults with and without disabilities, for it recalls vividly the difficulties encountered by trying to establish a genuine sense of belonging. (Appropriate for grades 6 and up.)

Sachs, Ann. (1981). *Just like always*. New York: Antheneum.

Janie and Courtney have similar disabilities (scoliosis) and must cope with a prolonged hospital stay. The two girls are very different. Janie is outspoken, mischievous, always questioning the arbitrary hospital rules and exploring limits. Courtney, a shy, quiet girl, "has always been a model patient" and lives in a fantasy world. It is through the very different personalities of the two girls that the reader subtly realizes that individuals with the same disabilities are just that—individuals. The story takes place in the hospital and does dwell more on hospital routines, personalities, and insensitivities than on disability. (Appropriate for grades 4-7.)

Walker, Lou Ann, photographs by Michael Abramson. (1985). *Amy: The story of a deaf child*. New York: E.P. Dutton.

Amy Rowley, who is deaf, loves to climb trees, swim, read, and watch movies. She is learning to skateboard and is the fastest runner of the girls in her class. This photo essay, told in Amy's own words, shows an active child and provides the reader with much information about how people who are hearing impaired do many things, e.g., talk on the telephone via a TDD or know that the doorbell is ringing through a series of flashing lights. (Appropriate for grades 3-6.)

EDUCATIONAL MATERIALS FOR PARENTS AND PROFESSIONALS

Educational Equity Concepts. *Mainstreaming for equity: Activity and resource kits*. New York: Author. (Available from Educational Equity Concepts, Inc., 114 East 32 Street, New York, NY 10016.)

An innovative curriculum for all children, disabled and nondisabled, in kindergarten through sixth grade. The curriculum comes in self-contained kits that hold everything needed to teach the activities. Included are hands-on materials (books, posters, charts, photos, wooden figures, lotto games, braille slates and styli), as well as a step-by-step curriculum guide that contains ideas for activities and projects that present a unique approach to the language arts and social studies curriculum. All the resources are multicultural, free of gender stereotypes, and present a positive view of children and adults with disabilities. *The family and school kit, for grades K-2* focuses on familiar themes through which children learn about hearing impairment and mobility impairment. *The communication kit, for grades 3-6* expands concepts of communication using braille in a unit on visual impairment and sign language in a unit on hearing impairment.

Educational Equity Concepts. *Mainstreaming for equity posters*. New York: Author.

A set of three unique posters depicted disabled and nondisabled children and adults interacting in a variety of situations: at home, in school, and in the community. The multicultural posters—Families, School, and Communication—are black and white with bright red borders. The titles are in bold print, American Sign Language, and braille. The size is 17" x 22". Included in kits, but available separately.

Froschl, Merle; Colon, Linda; Rubin, Ellen; & Sprung, Barbara. (1984). *Including all of us: An early childhood curriculum about disability*. New York: Educational Equity Concepts, Inc. (Also distributed by Gryphon House, 3706 Otis Street, P.O. Box 275, Mt. Rainier, MD 20712.)

Learning about disabilities enriches and extends the traditional early childhood curriculum in significant ways. It offers enormous benefits to children's cognitive, social, and emotional growth. It remarkably increases parent/child and home/school communication. This book tells why and how. The activities in this guide are grouped into three curriculum areas: Same/Different, incorporating hearing impairment; Body Parts, incorporating visual impairment; and Transportation, incorporating mobility impairment.

National Clearinghouse for Women and Girls with Disabilities. (1990). *Bridging the gap: A national directory of services for women and girls with disabilities*. New York: Author. (Available from Education Equity Concepts, Inc., 114 East 32 Street, New York, NY 10016.)

The Resource Directory includes lists of organizations that primarily serve women with disabilities. In the last several pages, the organizations are classified by category and listed by city and state.

Organization for Equal Education for the Sexes. *Women with disabilities posters*. Brooklyn, NY: Author. (Available from Organization for Equal Education of the Sexes, 808 Union Street, Brooklyn, NY 11215.)

Eleven posters, featuring women with disabilities, can be ordered separately or as a set. A brief biography is included with each poster. Included are: Alicia Alonso, Susan B. Anthony, Elizabeth Blackwell, Linda Bove, Annie Jump Cannon, Fannie Lou Hamer, Helen Keller, Billie Nave Masters, Wilma Rudolph, Harriet Tubman, and Bree Walker.

Phillips, Elizabeth. *Equality intropacket: Women and girls with disabilities*. Brooklyn, NY: Organization for Equal Education of the Sexes. (Available from Organization for Equal Education of the Sexes, 808 Union Street, Brooklyn, NY 11215.)

An outstanding and comprehensive packet of materials, most appropriate for educators interested in changing attitudes and curricula around issues of disability and gender. Complete with resource list and bibliographies for children, adolescents, and adults.

ABOUT WOMEN WITH DISABILITIES

Browne, S.E., Connors, D., & Stern, N. (Eds.). (1985). *With the power of each breath*. San Francisco: Cleis Press. (Available from Cleis Press, P.O. Box 8933, Pittsburg, PA 15221.)

Anthology written for, by, and about women with disabilities. All of the 54 women who contributed are disabled. The editors state that, "These pages are a journey into our lives as we survive in an inaccessible society, express our anger, grow up in our families, live in our bodies, find our own identity, parent our children, and find our friends and each other."

Campling, J. (1981). *Images of ourselves: Women with disabilities talking*. Boston: Routledge & Bogan Paul.

Presents rich and compelling stories using the words of women with disabilities. The women vary in age, disability, politics, and lifestyle. (Available on cassette from Recording for the Blind. A companion film is also available.)

Carrillo, A.C., Corbett, K., & Lewis, V. (1982). *No more stares*. Berkeley, CA: Disability Rights Education and Defense Fund, Inc. (Available from DREDF, 2032 San Pablo Avenue, Berkeley, CA 94702. Telephone: (415) 644-2555.)

Through photos and brief personal accounts, more than 100 girls and women with disabilities are depicted at home, school, sports, personal, and family activities. A highly successful attempt to shatter stereotypes about women with disabilities. Essential reading for teenagers, their parents, and the professionals who work with them. Contains a 22-page annotated resource list. (Also available on cassette.)

Deegan, M.J., & Brooks, N. (Eds.). (1984) *Women and disability: The double handicap*. New Brunswick: Transaction Books. (Available from Transaction Books, Department 2510, Rutgers University, New Brunswick, NJ 08903.)

A set of essays reviewing the economic, social, and psychological conditions of women with disabilities. (Updated from the *Journal of Sociology and Social Welfare*, July 1981, special issue on women with disabilities.)

Fine, M., & Asch, A. (Eds.). (1988). *Women with disabilities: Essays in psychology, culture, and politics*. Philadelphia, PA: Temple University Press.

This 348-page book takes a comprehensive look at the issues that face women with disabilities in our society today. It amply illustrates the double bind that women with disabilities confront in trying to succeed as individuals, professionals, lovers, and family members in a society that devalues and discriminates against them.

Lonsdale, S. (1990). *Women and disability: The experience of physical disability among women*. New York: St. Martin's Press. (Available from St. Martin's Press, 175 Fifth Avenue, New York, NY 10010.)

Detailed interviews with disabled women of all ages describe the experience of physical disability. The impact of gender upon being or becoming disabled is discussed, as well as self-image, sexuality, relationships, marriage and childbearing.

Mitchell, J.S. (1980). *See me more clearly: Career and life planning for teens with disabilities*. New York: Harcourt Brace Jovanovich. (Available from Harcourt Brace Jovanovich, 757 Third Avenue, New York, NY 10017.)

This guide is useful when thinking about and planning for a career. It includes tips for adolescents with disabilities on dealing with teachers and counselors who may be unsympathetic or uninformed about disability issues.

Rousso, H. (with O'Malley, S.G., and Severance, M.). (1988). *Disabled, female and proud! Stories of ten women with disabilities*. Boston, MA: Exceptional Parent Press. (Available from the Networking Project for Disabled Women and Girls, YWCA/NYC, 610 Lexington Avenue, New York, NY 10022.)

The ten women profiled in this book prove that making choices about school, work, family, and love is what being disabled, female, and proud is all about.

Saxton, M., & Howe, F. (Eds.). (1987). *With wings: An anthology of literature by and about women and/or girls with disabilities*. New York: The Feminist Press.

Through personal accounts, fiction, and poetry, women describe the physical and emotional experience of disability. The selections dispel the myths and stereotypes and celebrate the strengths and talents of women and girls with disabilities.

Traustadottir, R. (1990). *Women with disabilities: Issues, resources, connections*. Syracuse, NY: Human Policy Press. (Available from Human Policy Press, 200 Huntington Hall, 2nd floor, Syracuse, NY 13244-2340. Telephone: (315) 443-3851.)

Excellent and extensive annotated bibliography and listing of resources, teaching materials, services, support groups, organizations, and periodicals.

Women and Disability Awareness Project. (1989). *Building community: A manual exploring issues of women and disability*. New York: Educational Equity Concepts, Inc.

Examines the connections between discrimination based on gender and on disability. Contains background information on disability rights and on women and girls with disabilities, workshop format, an annotated bibliography, and selected readings. This expanded edition also contains a supplement (including a workshop format and related materials) that focuses on meeting the special needs of teen women with disabilities.

VIDEOS AND FILMS

Access Oregon. (1990). *Don't go to your room... and other affirmations of empowerment for women with disabilities.* (Available from Women's Educational Equity Act Publishing Center, Education Development Center, 55 Chapel Street, Suite 200, Newton, MA 02160. Customer Service : 1-800-225-3088.)

In this 60 minute video, women with disabilities talk openly about their lives in terms of jobs, sexuality, abuse, health, parenting, family, and ways of empowering oneself. (Available in 1/2" VHS, for sale or rent, captioned, or non-captioned.)

California State/Sacramento Media Services. (1986). *From disabled to abled.* (Available from University Media Services, California State University, Sacramento, 6000 J Street, Sacramento, CA 95819.)

A 30-minute video in which three mentally retarded women from diverse backgrounds are interviewed about their lives. Each of the women discusses issues of family, relationships, education, and employment, as well as independence, love and societal attitudes toward them and their disability.

Chapman, L., Leblanc, P., & Stevens, F. *See what I say.* (Distributed by the Filmmakers Library, 133 E. 58 Street, New York, NY 10022.)

In this film, Holly Near, a feminist folk singer, breaks through the barrier that separates the hearing and the deaf community. She shares her concert with Susan Freudlich, recognized American Sign Language interpreter, who incorporates mime and dance in the translation of lyrics. Their sychronized performance heightens the impact of her vision of a better world. The powerful stories of four women and their experience with deafness are told in the film. For example, one woman relates that when she grew up: "Sign language was forbidden. Even if I waved 'hi' I would get hit." *See What I Say* ends with a sense of shared communication between hearing and deaf cultures. (16mm, color, 24 minutes)

Daley, E., & Kaplan, C. (1983). *Tell them I'm a mermaid.* Los Angeles: Taper Media Enterprises, Embassy Television, KTTV/Metromedia Television. (Distributed by Embassy Telecommunications, 1901 Avenue of the Stars, Los Angeles, CA 90067.)

First aired on network television in December 1983, this unique musical-theatre documentary tells of the lives of seven women with physical disablities. Using an original music score and choreography, the women use their personal experiences to refute society's stigmas and stereotypes about disabilities. (16mm, color, 23 minutes, also available in 3/4" and 1/2" videocassette)

Harrison, J., & Rousso, H. (1989). *Positive images: Portraits of women with disabilities.* (Developed by the Networking Project for Disabled Women and Girls, and Julie Harrison Productions. To order, contact the Networking Project for Disabled Women and Girls, YWCA/NYC, 610 Lexington Avenue, New York, NY 10022.)

Portrays three women with disabilities: Deidre Davis, attorney and civil rights activist who is paraplegic; Barbara Kannapell, psycholinguist and well known scholar and lecturer on the culture of deafness; and Carol Ann Roberson, Director of the New York City Mayor's Office for the Handicapped and mother of two teen-age daughters, who is quadriplegic. The videotape presents the women in all aspects of their lives: their work, their politics, and their loves. (1/2" videotape, color, 60 minutes)

Like other people. (Available from Perennial Films, 477 Roger Williams, P.O. Box 855, Ravinia, Highland Park, IL 60035.)

A film about two individuals with cerebral palsy who meet, fall in love, and marry. Has some beautiful scenes that show that sometimes the inability to find a mate can relate to problems of personality and self-image, rather than to one's impairment.

National Film Board of Canada, producers. (1989). *The impossible takes a little longer.* (Order through: Indiana University, Audio-visual Center, Bloomington, IN 47405; Telephone: (812) 855-8087.)

Portrays the personal and professional lives of four women with disabilities: one is mobility impaired, one is deaf, one is in a wheelchair, and one is blind. In spite of encountering many obstacles (which they discuss), these women have developed successful work and home lives. As one puts

ORGANIZATIONAL RESOURCES

Educational Equity Concepts, Inc. 114 East 32 Street, New York, NY 10016. (Telephone: (212) 725-1803.)

Educational Equity Concepts, Inc. was founded in 1982 to foster equal educational opportunity. This nonprofit organization produces innovative programs and materials to help eliminate sex, race, and disability bias, and offers a broad range of training and consulting services.

National Clearinghouse on Women and Girls with Disabilities. Operated by Educational Equity Concepts, Inc. 114 East 32 Street, New York, NY 10016. (Telephone: (212) 725-1803.)

The Clearinghouse is creating a computerized means of gathering information, providing resources and referrals, developing a communication network, and conducting public education regarding women and girls with disabilities. "Disabilities" is defined to include physical, sensory, language, cognitive, emotional, and health disabilities.

The Networking Project for Disabled Women and Girls, YWCA/NYC, 610 Lexington Avenue, New York, NY 10022.

This project, initiated through the efforts of Harilyn Rousso, provides adolescent girls with disabilities with opportunities to meet older disabled women leading interesting, satisfying lives. Women and girls with disabilities get together through conferences, workshops, worksites, for one-on-one encounters, and special events. They have open discussions on topics ranging from jobs to relationships to sex. The Project is now being replicated in other cities around the nation.

Disabilities Unlimited, 3 East 10 Street, New York, NY 10013. (Telephone: (212) 673-4284.)

Directed by Harilyn Russo, Disabilities Unlimited provides counseling and psychotherapy to individuals and consultation and training to organizations on issues of women and disability.

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NICHCY thanks our Project Officer, Sara Conlon, at the Office of Special Education Programs, U.S. Department of Education, for her time in reading and reviewing this document. We also thank Dr. Margaret McLaughlin, of the Institute for the Study of Exceptional Children and Youth, University of Maryland, and Judy Barokas at the Council for Exceptional Children, for their expenditure of time and for providing their expertise in reviewing this manuscript. Finally, we thank Educational Equity Concepts, Inc., for their contributions to the material in this issue.

This document was prepared for publication on the Macintosh®SE and LaserWriter®II NT through the generosity of Apple Computer®, Inc.

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This document was developed by Interstate Research Associates, Inc., pursuant to Cooperative Agreement #G0087C3051 with the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

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